

Service Delivery Subcommittee Meeting Minutes  
February 21, 2007

Attendees: Barbara Biglieri, Christy Torkildson, Devon Dabbs, Joetta Wallace, Liz Sumner, Lori Butterworth, Sally Sehring, Sheryl Gonzalez, Chester Randle, Xavier Castorena, Pam Christiansen, Dennis Owen, Kathy Bissell-Benabides, Carmen Romo, Barbara Lemus, Christine, King, Belva Kinstler, Erin Winter, Jan Burrow. Teleconferencing participants: Gay Walker, Margaret Clausen, Michael Joseph.

Agenda:

- Review Definitions for critical services: Care Coordinator, Palliative Care, Hospice, Child Life Specialist. Definitions provided to the group from participants at previous meeting.
- Identify required elements of a palliative care program. Participants review materials including National Quality Forum's (NQF) National Framework and Preferred Practices for Quality Palliative and Hospice Care and bring their own expertise.

Announcements:

Eligibility Decisions from subcommittee meeting. Eligibility subcommittee recommends adopting Conditions appropriate for Pediatric Palliative Care. These are listed in the New England Journal of Medicine, Himmelstein, Volume 350(17), April 22, 2004, Pages 1752-1762. To further define medical necessity among this group, the Washington Eligibility Model will be used to identify at least three of 6 circumstances that would indicate medical necessity. These documents were passed out at the meeting.

CCS Numbered Letters were placed on the website. NL 04-0207, Palliative Care Options for CCS Eligible Children and NL 05-0207, Authorization of Short Term Shift Nursing Services were both released last week. These services focus on educating the local programs on the CCS policy for existing Medi-cal benefits that could be authorized as palliative care services. This is not an announcement of a comprehensive program, but to clarify what benefits may already be authorized for children who need these services and to encourage county offices to start thinking about palliative care.

Discussion/conclusions: Definitions

No need to determine definition of Hospice and the word its inherent meaning of eminent death have no place in Waiver for pediatric palliative care. Delete term and focus on Palliative Care Service. No need to define hospice separately since hospice is included within palliative care. Group consensus to use palliative care as an umbrella term, encompassing, among others, pain and symptom management, psychosocial, emotional and spiritual support and hospice..

Define the term of Pediatric Palliative Care (PPC) utilizing the NQF definition with a few inclusions: Include interdisciplinary, multiple settings, potentially life limiting medical conditions, developmentally appropriate, and bereavement services.

**Action:** CCS staff to revise the NQF definition to include those descriptions/requirements. This revision is offered for adoption at the next meeting.

“Pediatric palliative care means **interdisciplinary, developmentally appropriate** patient and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering from **potentially life threatening conditions**. Palliative care throughout the continuum of illness to **bereavement**, may take place at **multiple sites** and involves addressing physical, intellectual, emotional, social and spiritual needs and will facilitate patient autonomy, access to information and choice.”

Palliative Care Coordinator:

Care coordination must be utilized at the local level as fee for service versus globally administrative so as not to be construed as case management. Care coordination is different from case management. Primary function of care coordination is “hands on” communication with patient, family and team along with providing patient advocacy with service providers.

General duties would include developing a plan of care with family and MD team, working with the family to define goals and evaluate/modify as necessary, monitoring the care plan and making adjustments. Has knowledge of PPC service package, coordination with local community services, and insuring good transition from each location of care. Participates in team conferences and utilizes parent involvement.

Caseload seems to limit models to 1-20. Acuity may be considered so that level could be elevated if a mix of high use and low use patients

Qualifications: Licensure in a professional discipline that is eligible to become a Medi-Cal provider. Care coordinator will need pediatric training yet to be determined. ELNEC, linking with parents and other specific pediatric training such as developmental knowledge might need to be demonstrated. Waiver unit advises to not make experience qualifications too difficult, so that will be difficult or too expensive to obtain. We want people to become providers. Also, waiver unit experience recommends that a license requirement will be easier to approve

**Action:** Group to bring existing models of Pediatric Palliative Care Coordinator duty statements and minimum qualifications currently being used in agencies or examples of other states roles. Supporting evidence/data for caseload recommendations to support caseload standards should be provided.

Discussion: Child Life Specialist

Needs to be integrated into local resource team. Minimum qualifications are that accreditation is provided by a national organization that reviews curriculum and training opportunities and provides credential. Is a minimum baccalaureate but moving towards a masters prepared discipline. Christy Torkildson had submitted a definition that she felt was a good standard, but it was never received.

**Action:** Postpone discussion until role and minimum standards are available. Christy will email to state CCS.

Discussion: What Do Services Look Like?

Licensed agencies who are already Medi-Cal providers such as freestanding hospice agencies and home health agencies which are also licensed as hospice providers are the likely providers. While some additional pediatric training will need to be developed and the concept of Care Coordinators need to be expanded, these providers are the most prepared of existing providers to begin services. Waiver unit re-emphasized the easy acceptance of licensed providers. 24 hour call requirements may already be a license requirement. Discussion ensued on the ability to verify a system of 24 hour call and how one might look over and above minimum requirements.

**Action:** State CCS will look into licensing requirements of existing licensed agencies and how those are quantified at licensure and certification.

The role of parents in the development of the project was discussed. Discussion revolved around the possible role of parents to participate as board members, care coordinators or in some other advisory capacity to provide feedback on the sensitivity of agency services to parents. Parent involvement can provide professionals with a roadmap of potential difficulties and recommend specific approaches to patients and their families. Does this need to be a waiver component as it would require this element for service to be provided? Waiver unit recommends to keep it simple and adopt these enhancements as a component to participate. While parents may be effective service coordinators, it is difficult to quantify these qualities using objective minimum qualifications.

Flow of information from MD to Care coordinator was considered. Patient is likely to be already CCS eligible and is being seen at a special care center (SCC) or specialty provider (SP). Either entity would refer to the care coordinator at the licensed agency. The Care coordinator would evaluate the patient and family and would develop a plan of treatment and integrate with other existing treatment plans for the patient/family. Approval of plan of treatment would allow services to begin, include locally available services, that may not necessarily be benefits. Care coordinator would revise the plan of treatment as needed with the family and SCC/SP. Coordination with CCS is not clearly defined, but assumed.

**Action:** State will attempt to describe flow of service delivery via flow chart.

Recommendations from Barbara Lemus, Chief of Waiver Unit resulting from listening to discussion:

- **Stick to one plan.** Do not develop different models for each area. Evaluating costs will be difficult enough and will be confusing at the federal level. Changes or modifications can be made after the model is proven successful by amendment. While there is some flexibility from site to site, pilots must be providing core services to meet minimum standards.
- **Define one plan.** Clarify how the plan described in the waiver is different from the State Plan.
- **Need to guarantee a minimum level of service.**
- **Use licensed agency and or personnel.** She recommends reviewing the RN and SW roles in AIDS waiver. She will arrange email of AIDS waiver model.
- **Clearly describe rates.**

Next Meeting 3/20/07 10:00 am to 3:00pm

Review Case Coordinator roles and identify core duties.

Develop Flow Chart

Prepare Recommendations for core waiver services to advisory committee.